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Chronic What Now?



Written by Megan Brady

Illustrated by Elissa Galiley

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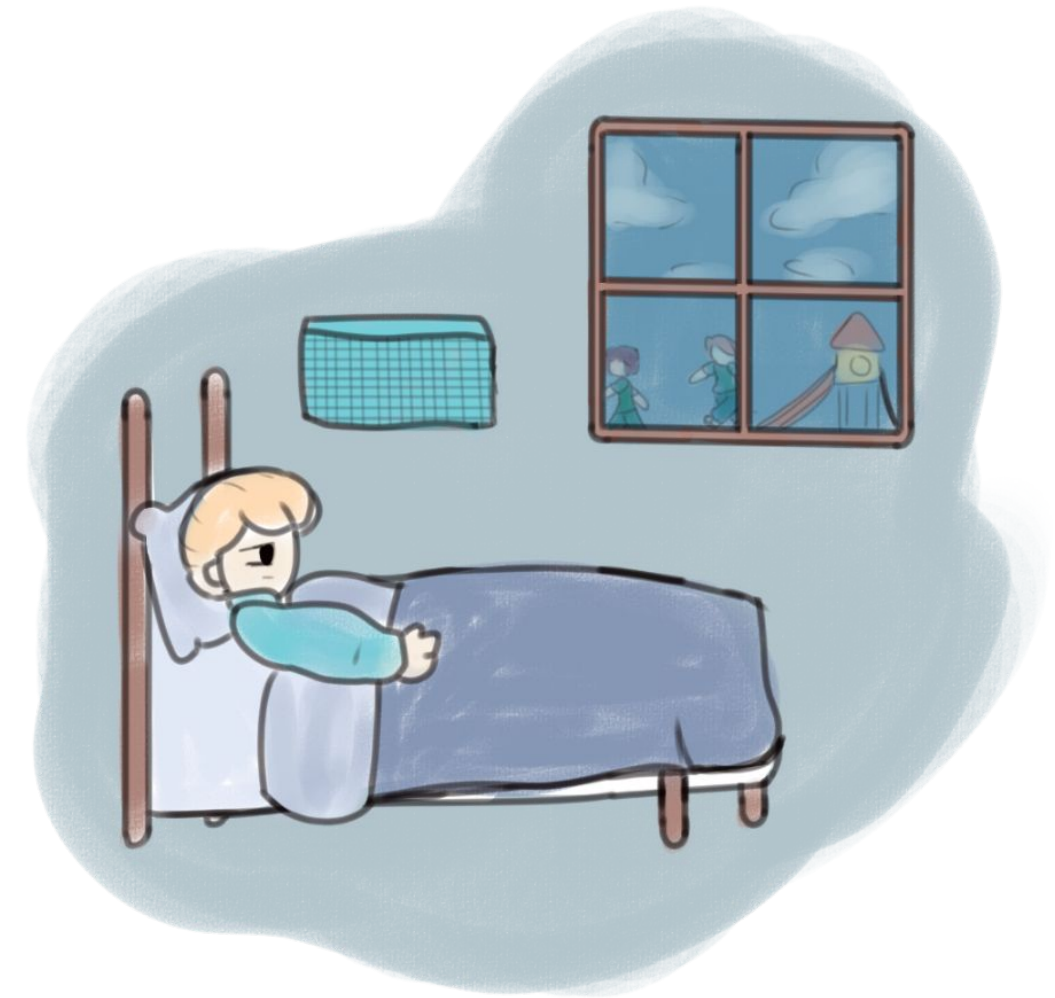


Project

For everyone who's helped me get to
where I am today

When you're sick, everything seems harder - right? You're always tired, and you don't want to do anything. Now imagine if you stayed sick for over a year!

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If you did, you'd have something called a [chronic illness](#).

A **chronic illness** lasts a really long time.



People who have one might get better in a year or two, or it may last their whole life.

There are a lot of chronic illnesses, and they're all a bit different.



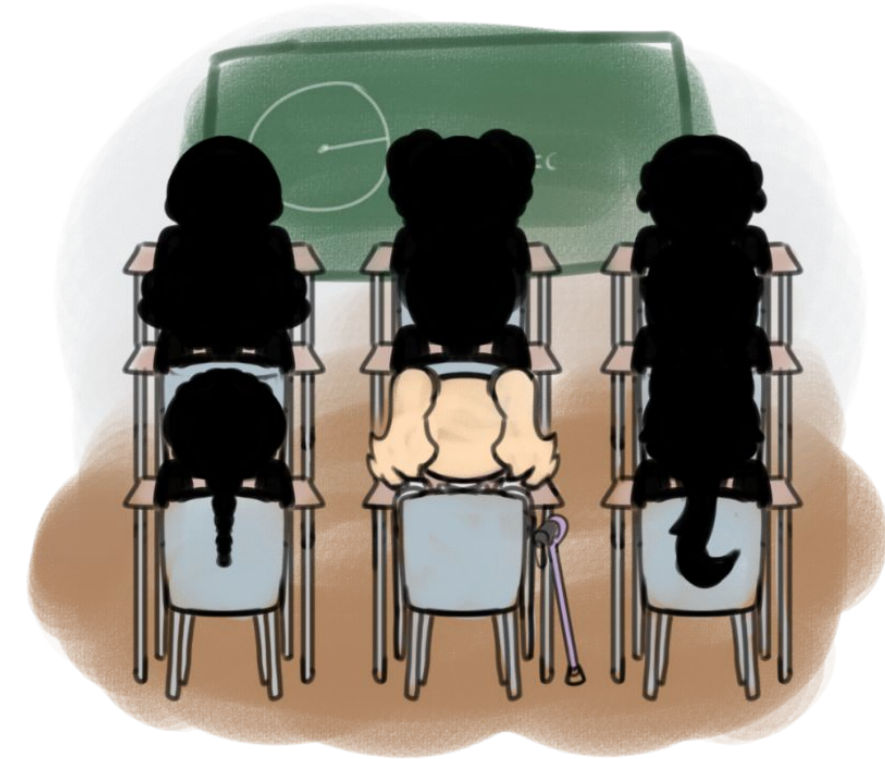
Most of them can make you tired, or make your body hurt.

Anybody can get a chronic illness. You can't always see them, and it doesn't matter how old or young you are.



One of your friends at school could have one, or one of your teachers.

Even though anybody can get a chronic illness, not many people do.



Three of the most common chronic illnesses, POTS, MS, and CFS, affect less than 1% of people in the US. That's only one person in every one hundred people.

The different ways chronic illnesses make you feel bad are called **symptoms**.



Symptoms can be lots of things, like being tired, or confused. Most illnesses have different symptoms.

Even two people who both have the same illness might have different **symptoms**.



For example, one person may just feel tired, while another feels like they're going to throw up.

A person with a chronic illness might feel different than they did the day before, and different again the next day.



They might be able to run a race one day, and not be able to get out of bed the next.

Another person might be too tired to do anything one day, then be able to go to the zoo the next.



Symptoms aren't always the same everyday.

Some people might need to use a **mobility aid** to help them.



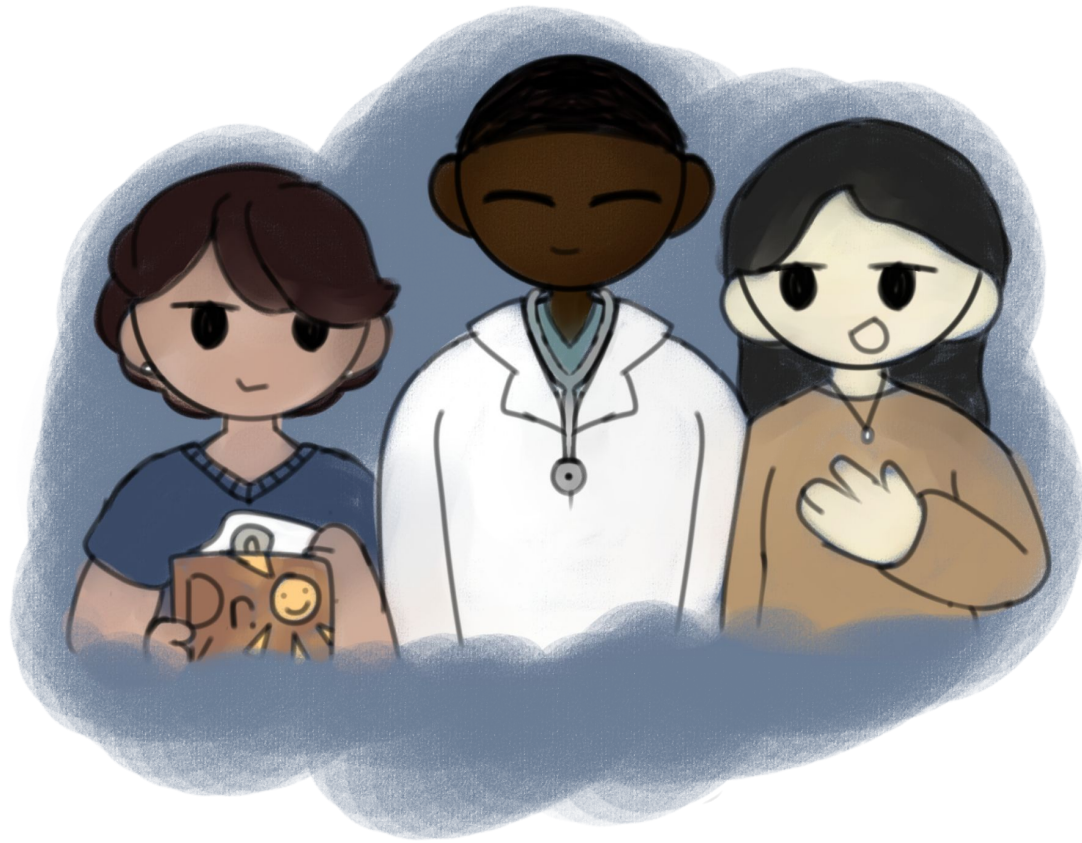
A **mobility aid** is something that helps a person move, like a cane or wheelchair.

Even though mobility aids look super fun and cool, it's really important that you don't touch them without permission.



Imagine if somebody grabbed your leg without asking- not cool, right?

There are fancy, extra-special doctors that know more about chronic illnesses than others.



Because these doctors are so special, we call them **specialists**!

People with chronic illnesses might have to go to lots and lots of appointments with their **specialists**.



Sometimes, these visits can be scary, or hard, but they're super important.

Chronic illnesses come with a lot of change, and that can make a lot of big feelings for the sick person, and for their friends.



Anything you feel is absolutely okay. You could be sad, or mad.
You could even be jealous or embarrassed.

Grown-ups might also be having big feelings, and that's ok too.



(Even though it can be scary!)

Someone with a chronic illness can still do almost anything they want. They just might need some [accommodations](#).



[Accommodations](#) are anything that helps someone do the things they want to do- like using a mobility aid!

Remember, a diagnosis of a chronic illness isn't the end of the world. It means there will be some change, but as long as they have support, someone with a chronic illness can still live life to the absolute fullest- whatever that means for them.



Acknowledgements

Thank you so much to everyone who's helped me along my journey, but I'd like to give special thanks to the following people:

Everyone at Texas Children's who has helped me overcome my obstacles,

The teachers and administrators at Cypress Creek High School who helped me graduate on time,

My friends and family, whom I don't know what I'd do without,

and of course,

My Gold Award team: Michelle Madron, Mary-Beth Cardarette, Nikki Larsen, Karen Brady, Elissa Galiley, and Denva Dayal

About the Author

Megan Brady was diagnosed at age 15 with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (ME/CFS). Despite not being able to attend school full time for over a year, she still graduated on time with her class. She was able to earn her Eagle Scout rank in Scouting America, and then set her sights on Gold Award.

The most prestigious achievement in Girl Scouting, the Gold Award requires Scouts to spend 80 hours on a meaningful project. When she was diagnosed with CFS, Megan struggled to find resources that explained her illness in an understandable way, and didn't focus primarily on chronic pain. When faced with choosing a Gold Award project, she decided to help make the resources she had been unable to find.

Other Helpful Resources

When Your Child Has a Chronic
Medical Illness

A Guide to The Parenting Journey



<https://tinyurl.com/HCPL-Chronic>

AACAP

Chronic Illness and
Children



<https://tinyurl.com/AACAP-Chronic>

Inside of back cover

KidsHealth

Caring for a Seriously or
Chronically Ill Child



<https://tinyurl.com/Kids-Chronic>

Texas Children's Hospital

Psychological Complications of
Chronic Illness



<https://tinyurl.com/TCH-Chronic>

An easy-to-understand, colorful children's
book explaining chronic illnesses, and
what it means for both the person
diagnosed and those around them

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